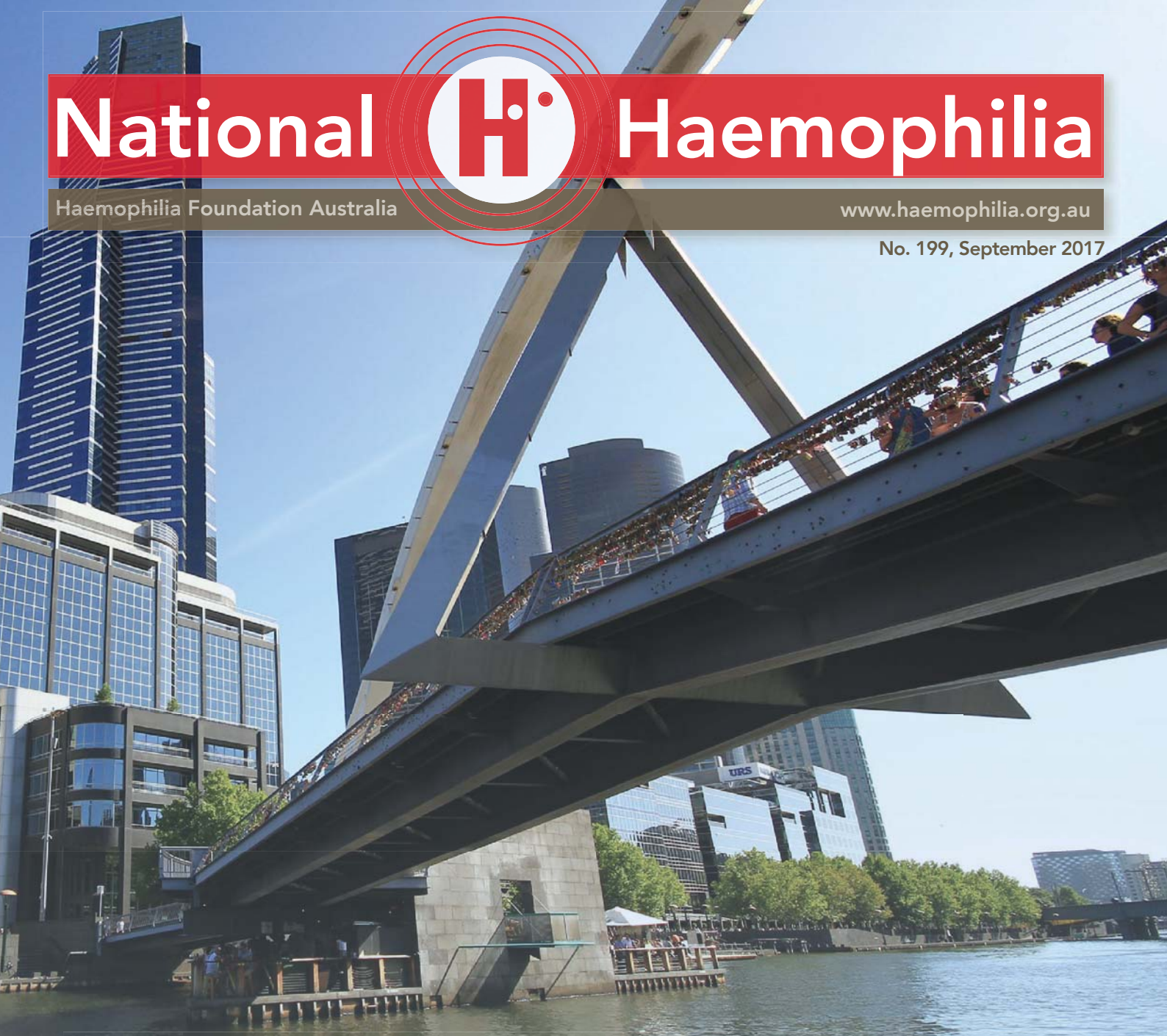
National Haemophilia

Haemophilia Foundation Australia

www.haemophilia.org.au

No. 199, September 2017



COMING SOON

18TH AUSTRALIAN & NEW ZEALAND CONFERENCE ON HAEMOPHILIA & RARE BLEEDING DISORDERS

LOOKING FORWARD TO CHANGE

Melbourne • 12-14 October **2017**

CONTENTS

Haemophilia Foundation Australia
Registered No.: A0012245M
ABN: 89 443 537 189
7 Dene Avenue Malvern East,
Victoria, Australia 3145
Tel: +61 3 9885 7800
Freecall: 1800 807 173
Fax: +61 3 9885 1800
hfaust@haemophilia.org.au
www.haemophilia.org.au
Editor: Suzanne O'Callaghan

Photographic Usage:
Skyseeker/Hamza Butt

BLEEDING DISORDERS AWARENESS WEEK

Bleeding Disorders Awareness Week is an opportunity for individuals and families as well as Haemophilia Foundations and other organisations to take part in a campaign and activities to raise awareness about haemophilia, von Willebrand disorder and related bleeding disorders throughout Australia during the week of 8-14 October 2017.

HFA is calling on our friends and supporters to help us by taking part in Red Cake Day!

HOW CAN I GET INVOLVED?

- Organise a Red Cake Day at your home, workplace, school, kindergarten or community group
- Order free napkins, pens, tattoos, stickers and colouring sheets and pencils to make your Red Cake Day special
- Display free posters, postcards, newsletters and raise awareness about haemophilia, von Willebrand Disorder and other related bleeding disorders
- Tell your friends, family, colleagues about Awareness Week and encourage them to hold their own Red Cake Day event!

Once again Bendigo Banks across Australia will be supporting Red Cake Day. Pop into your local branch during the week.

To order your free promotional items, visit www.haemophilia.org.au/redcakeday

FOR MORE INFORMATION

- visit www.haemophilia.org.au/redcakeday
- or call HFA on 1800 807 173
- or email Natashia ncoco@haemophilia.org.au.

Like HFA on Facebook
www.facebook.com/RedCakeDay

Follow HFA @Haemophilia_Au and join the conversation at #redcakedayhaemophilia

Red Cake Day

2017

A PART OF

Bleeding Disorders Awareness Week

8-14 OCTOBER

Red Cake Day

Help raise awareness and funds for people living with bleeding disorders in Australia by participating in Red Cake Day during Bleeding Disorders Awareness Week.

Red Cake Day is an opportunity for individuals, families, schools and workplaces to take part in a special fundraising event to raise funds and awareness about Bleeding Disorders.

To get involved visit
www.haemophilia.org.au
or call HFA on 1800 807 173

HAEMOPHILIA FOUNDATION AUSTRALIA

Gavin Finkelstein is President, Haemophilia Foundation Australia

FROM THE PRESIDENT

Gavin Finkelstein

This edition of *National Haemophilia* will arrive in your letter box or inbox a few weeks before our national conference to be held in Melbourne. The conference program covers a wide range of topics, and issues that we think are of interest to people affected by bleeding disorders.

I have been to most conferences over the last 15- 20 years and I always think they are a great chance for people with bleeding disorders to meet up and share their own experiences and to learn from each other. The social aspect is really enjoyable, especially when meeting up with people you haven't seen for a while. I know in particular, lots of younger people in our community don't get the chance to meet others with bleeding disorders, nor do they have the chance to discuss some of the difficulties of living with a bleeding disorder because they are really busy or just don't come across others like themselves.

The other great thing about conferences is that we usually have people from every age and life stage in the audience and as speakers at the conference. Ours is a community of experts and our speakers are experts - either because they are making a good fist of living with a bleeding disorder that impacts every part of their lives, or because they have had many years' experience of working with or treating people with bleeding disorders.

So, there is something for everyone – for health professionals to learn more about what it's like to live with a bleeding disorder, or about new treatments, and for people with a bleeding disorder and their families and carers who are keen to find out the latest information and hear about others' experience.

Younger parents like to meet others like themselves, because they often feel really alone when faced with a child newly diagnosed with a bleeding disorder. But they also like to meet people who have come through the early years of having a baby with a bleeding disorder and see how other people adjust and in turn become the experts following their day to day experiences, just as they will do! They also like to see the young men and women in our community who have grown up and are now leading active, independent and fulfilling lives. Some of these young people have participated in our youth leadership programs and can share their experiences.

For some in our community, there will be very new information about treatment and care – we are in a fast moving period as many new treatments are becoming available, and this is leading us to think about new approaches to treatment and what we can and should expect from our treatment. We have been talking to women and girls in our community, and as well as producing print and online education resources, we have invited speakers for conference sessions that are geared to some of the complex issues that arise for women and girls. Other sessions will focus on fitness and exercise and others will focus on some of the challenges faced by older members of our community.

In many ways, our conference is very representative of our community. It includes the many parts – it identifies the challenges, offers solutions, and helps us make connections that enable us to get on with our lives.

We still have some limited funding available if you wish to attend and need some help. Please contact Sharon Caris at HFA for information about funding scaris@haemophilia.org.au or 03 98857800.

2017 CONFERENCE

It's not too late to register for the Conference – register online at https://www.secureregistrations.com/HFA2017/ or download a registration form at www.haemophilia.org.au/conferences.

The 18th Australian & New Zealand Conference on Haemophilia and Rare Bleeding Disorders will be held in Melbourne - from 12-14 October 2017.

Check out the program in this edition of *National Haemophilia* and you will see the variety of topics that are being covered and discussed during the two days. Also don't forget to register for the social functions – the Welcome & Exhibition Opening on Thursday evening (free-of-charge), Conference Dinner on Friday night and special Youth Meet and Greet on Friday night.

For the latest information visit www.haemophilia.org.au/conferences.

18TH AUSTRALIAN & NEW ZEALAND CONFERENCE ON HAEMOPHILIA & RARE BLEEDING DISORDERS

LOOKING FORWARD TO CHANGE

Melbourne • 12-14 October **2017**

CONFERENCE PROGRAM

THURSDAY 12 OCTOBER 2017

0830- 1700	Annual meetings of AHCDO, AHNG, ANZHSWCG, ANZPHG, DMG (health professional group members only)		
1830-1930	Welcome and Exhibition Opening – open to all registered conference attendees		
1930-2230	Youth VIP Meet & Mingle – for registered youth only		

FRIDAY 13 OCTOBER 2017

0830	Official Conference Welcome		
	Gavin Finkelstein		
0830-1000	Plenary 1 Dr Justin Coulsen ~ 21 days to a Happier Family		
	Dr Justin Coulson is one of Australia's most respected relationship speaker, author, and researcher. He will talk about keys to being a "happier family".		
1000-1045	MORNING TEA		
1045-1215	Concurrent 1 Hep C and HIV	Concurrent 2 Genetic Testing	Concurrent 3 Youth Myth Busting Session
	Chair: Suzanne O'Callaghan Hep C treatment personal story ~ Simon Hep C clinical update ~ A/Prof Joe Sasadeusz HIV clinical update ~ A/Prof Edwina Wright HIV personal story ~ Anthony Panel Discussion	Chair: Andrew Atkins *This session will focus on pathways to assessment and decision making about reproduction and pregnancy, counselling and planning.*	Chair: Moana Harlen *Help a panel of three teams with young people, adults and health care professionals on each panel bust myths about living with a bleeding disorder. Topics include sport, employment and disclosure among many more!*
1215-1325	LUNCH		
1325-1455	Concurrent 1 Von Willebrand disease	Concurrent 2 Understanding Pain	Concurrent 3 For families with a child newly diagnosed with a bleed disorder
	Chair: Dr Mandy Davis This session will cover VWD and the following issues: • testing and diagnosis • classification/types of VWD • variability of results and patient experience • integrating patient into HTC care • clinical management Speakers ~ Dr Mandy Davis & Dr Paula James	Chair: Cameron Cramey Understanding pain and pain science ~ Martina Egan-Moog A holistic approach: management strategies for persistent pain in PWBD ~ Dr Carolyn Arnold Clinical application of modern pain sciences for PWBD ~ Catherine Pollard	Chair: Dr Julie Curtin From a clinical perspective ~ Dr Julie Curtin Adjusting to diagnosis and the need for support ~ Dr Moana Harlen One family's journey with a bleeding disorder
1455-1535	AFTERNOON TEA		
1535-1700	Plenary 2 Prophylaxis		
	Chair: Dr John Rowell Snapshot of prophylaxis study and standardising joint score ~ Dr Jane Mason ABDR Data ~ Sumit Parikh		
1800	Remembrance Service		
1900	Conference Dinner *Tickets are $45 and must be pre-booked*		

SATURDAY 14 OCTOBER 2017

0700 - 0820	**Men's Breakfast** *Tickets are $30 and must be pre-booked*		
0700 - 0820	**Women's Breakfast** *Tickets are $30 and must be pre-booked*		
0830-1000	Plenary 3 – Women and bleeding disorders		
	Chair: Dr Jenny Curnow Considerations for women: diagnosis and living with a bleeding disorder; menorrhagia and other gynaecological issues; other bleeding symptoms/problems, complications, including anaemia and pain; inheritance and obligate carriers **Speaker ~ Dr Paula James**		
1000-1045	MORNING TEA		
1045-1215	Concurrent 1 Ageing		Concurrent 2 Improving care through MyABDR
	Chair: Leonie Mudge Issues for PWBD overview ~ **Leonie Mudge** Maintaining a physically active lifestyle ~ Joint replacement surgery and new developments ~ **Dr Huyen Tran** Insurance and superannuation ~ **Josh Mennen, Maurice Blackburn lawyers**		**Chair: Dan Credazzi** Why do we use MyABDR from a HTC AHCDO, NBA perspective ~ **Dr Chris Barnes** Working with the community ~ **Suzanne O'Callaghan** An HTC Royal Children's Hospital Melbourne experience ~ **Julia Ekert** MyABDR in the clinic and at home. Paediatric ~ **Dr Chris Barnes and Karan** Adult ~ **Andrew Atkins and Michael** Moving Forward with MyABDR ~ **Dr Chris Barnes** Panel and audience discussion
1215-1325	LUNCH		
1325-1455	Healthy joints in Adolescence for Life	Concurrent 2 Women and telling others	Concurrent 3 Free Papers
	Chair: TBC Recognising & managing bleeds, sport and physical activities, gym programs and basic principles, alternative sports and practical tips and advice such as RICE.	**Chair: Sharron Inglis** Genetic testing and a diagnosis – implications for insurance and employment – **Kim Shaw, Maurice Blackburn lawyers** Personal stories: Disclosure to partners, employers, health professionals, insurance ~ **Sharron** ~ **Susie** Panel/forum discussion, Q&A **Sharron, Susie, Dr Paula James, Kim**	**Chair: TBC** To Vein or Not to Vein? ~ **Robyn Shoemark** A new transition model from the Adult hospital perspective ~ **Jane Portnoy and Alex Coombs** Real Benefits of New Therapies for Children with Haemophilia ~ **Dr Julie Curtin** Peer Support in Victoria ~ **Julia Broadbent and Andrea McColl**
1455-1535	AFTERNOON TEA		
1535-1700	Plenary 4 – What's Here Now and on the Horizon - New Treatment therapies		
	Chair: Claude Damiani Supply and purchasing, new treatments, cost effectiveness assessment/funding pathways to new medicines ~ **John Cahill** Extended half-life factors and other new therapies ~ **Dr Huyen Tran** Gene therapy ~ **Prof John Rasko**		
1700	CONFERENCE CLOSURE		

This article is reprinted with permission from the online article published by the World Federation of Hemophilia on 27 March 2017 - https://news.wfh.org/lets-talk-period-an-interview-with-paula-james-md/

Prof Paula James is the international keynote speaker at the upcoming Australian & New Zealand Conference on Haemophilia and Rare Bleeding Disorders and will be presenting on medical issues for women and girls with bleeding disorders, along with Australian haematologists Dr Mandy Davis and Dr Jenny Curnow.

LET'S TALK PERIOD

WFH interviews Paula James

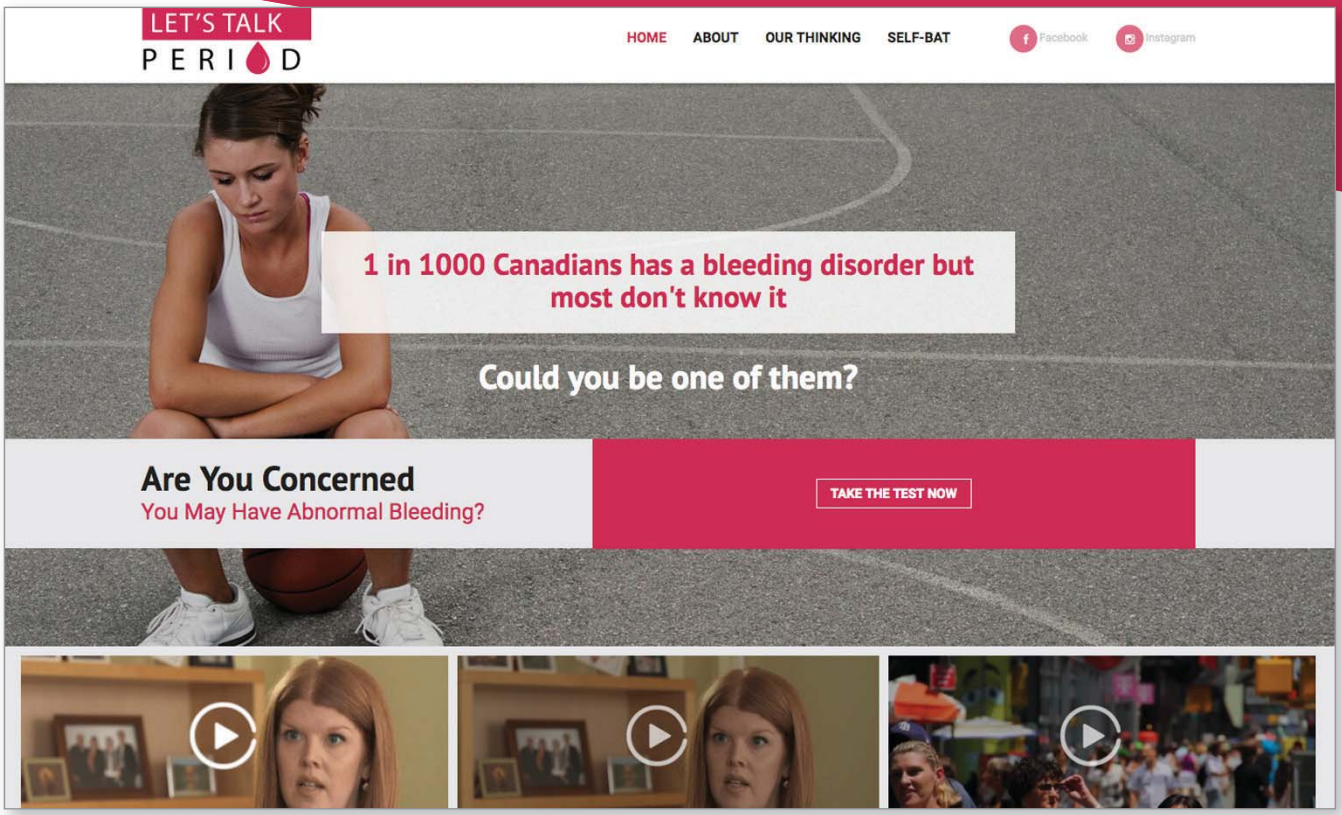
As the World Federation of Hemophilia (WFH) gears up for World Hemophilia Day 2017—and its theme of women and girls affected by bleeding disorders—the WFH had the pleasure of sitting down with Paula James, MD, an academic hematologist based in Kingston, Canada, for a question and answer interview.

She is the Medical Director of the Inherited Bleeding Disorders Clinic of Southeastern Ontario and the Women and Bleeding Disorders Clinic at the Kingston General Hospital. James is also a clinician scientist with a major focus on bleeding, von Willebrand Disease (VWD) and issues related to carrier bleeding. The WFH is very proud to have her on its von Willebrand Disease and Rare Bleeding Disorders Committee. We are also very proud that James is one of the first grant recipients of the WFH Clinical Research Grant Program.

James is now working on a project called **Let's Talk Period** which has the objective of increasing awareness of the signs and symptoms of bleeding disorders. The Let's Talk Period website offers a self-administered bleeding assessment tool (Self-BAT) that helps give people more information and advice about their bleeding and guides them toward the support they need.

During the interview, James was able to provide us with rich insight into the issues facing women and girls with bleeding disorders. The reality, she explained, is that many women are left undiagnosed and are not getting the treatment they need. Especially when it comes to menstrual bleeding, it is difficult to make the distinction between what is normal—and what is abnormal and requires additional attention. The social stigma surrounding women and girls talking about their period is another barrier in proper diagnosis.

The following is an excerpt from our interview with Paula James, MD, where she shares her experiences regarding Let's Talk Period and the positive impact it's having on the bleeding.



Q: Why did you decide to study women and bleeding disorders? What interests and motivates you about this subject?

A: My interest in women and bleeding disorders started with patient interaction. It became blatantly obvious to me very early on in my career that women were struggling. In some instances women were being cared for properly, but in many instances they weren't. I realized the frustration around the lack of recognition of the issues affecting women and I wanted to be part of the movement, to make people more aware of the issues at hand and to provide better diagnosis and care for these women.

It's not hard to treat women with bleeding disorders—in fact it's actually quite easy. It's not complicated medicine; we have a whole list of effective treatments we can use. What's important is that we make sure we are identifying the right patients and getting them to the right clinics so they can be cared for properly.

Q: Can you tell us more about the Let's Talk Period Project?

A: I had the general idea for Let's Talk Period five years ago. I was involved in developing bleeding assessment tools—also known as bleeding scores—which quantify the kind of bleeding that patients are experiencing. A lot of work went into validating an expert-administered bleeding assessment tool in primary care offices in Kingston, Ontario, with the goal of increasing referrals for bleeding disorders. Unfortunately the referrals didn't happen. We still don't recognize how often—when a woman says that she's having problem with her period—that the underlying problem is a bleeding disorder. We decided to go to the general public and put knowledge in the hands of people who might be suffering with symptoms. We took the expert bleeding assessment tool and turned it into something that could be self-administered. This was an evolved optimization process which included many rounds of revisions using feedback gathered from focus groups and from the way patients filled out the tool. We wanted to ensure that the bleeding score from the Self-BAT would be the same as with an expert administered tool. We are now able to provide people who complete the Self-BAT with a printable version of their results. If they find out that their bleeding is abnormal, there is a recommendation to speak with their physician about any concerns they may have.

We decided that we would use the internet—and especially social media—as a platform to get the word out. The website launched in May 2016 and the Facebook and Instagram pages launched in September 2016.

Q: What has been the response from the public? When the WFH shared your site on our social media channels the community reacted strongly with comments and shares.

A: I've been blown away by the response. I never fully understood the power of social media, especially as a knowledge translation and research tool. I knew it was an important topic, but didn't realize that there would be such an appetite for it.

There has been a steady growth on the website and on social media. As at March, 2017 there have been over 9,124 hits on the website, 1,154 people have taken the Self-BAT and 515 have an abnormal or positive score. Our Facebook account has 587 followers with a reach of 80,344 people. Our Instagram account has 82 followers.

>>

I would never have anticipated the global reach of doing this project—the hits on the website are from 83 countries.

Q: What do you hope for the future of the Let's Talk Period project?

A: I really would like to close the loop with the site. Right now, I don't know anything about what happens to people who take the test and have an abnormal score. Locally we would like to pilot a project where individuals in my catchment area would be invited to participate in a study that they would have to consent to and this would fast track them to our clinic for assessment and diagnostic testing. At the end of the test, we would like to build in a link to local clinics as much as we can, so people can have an idea of where they can get specialized care. We would also like to create links with practitioners who are willing to see patients and make the diagnosis.

Q: Do you have a message that you would like to share with the global community?

A: The message that I would like to share with the global community would be the following:

To our community and colleagues, I would say this: Let's Talk period has been a far more powerful tool than I ever imagined. It is a reasonable way to reach individuals who are suffering with bleeding and don't know it.

To the general public, I would say this: pay attention to your bleeding symptoms and seek help if you are concerned. Your symptoms can be easy to treat and there are lots of great options for treatment.

MESSAGE FROM THE WFH:

To learn more about the Let's Talk Period project, please visit letstalkperiod.ca. We encourage you to share this site with your network, to help increase awareness of women with bleeding disorders.

The WFH would like to thank Paula James, MD, for taking the time to share her experience with us on this important project.

HOW ARE BLEEDING DISORDERS DIAGNOSED IN WOMEN AND GIRLS?

Bleeding disorders in females are usually diagnosed through:

- The physical signs that a girl or woman has a bleeding tendency, eg bruising easily, nosebleeds, bleeding from the gums, very heavy periods; prolonged or excessive bleeding with minor cuts, or after dental surgery/extractions, other surgery and medical procedures, injuries or childbirth; joint or muscle bleeds.

And

- Checking the family history for others with a bleeding tendency.

And

- Laboratory tests on blood samples for her clotting factor levels or function and other signs of a bleeding disorder. In haemophilia genetic testing may also be involved to see if she has the altered gene causing haemophilia.

Bleeding disorders in females can be complex to diagnose and may need repeated testing and assessment by other specialists, such as a gynaecologist.

More information is available at www.haemophilia.org.au/women

This information was reviewed by Dr Mandy Davis, Ronald Sawers Haemophilia Centre, The Alfred hospital, Melbourne.

This article is adapted with permission from the blog published on Mindipalm.com on 23 August 2017

Mindi Palm is an Australian community member

LIFE WITH A LITTLE BLEEDER

Mindi Palm

Photos: Mindi Palm

On the 17th September, 2015, our son Elias was diagnosed with haemophilia. At the time, he was still a baby and only nine months old. We didn't even know there was such a thing as a bleeding disorder until that day the Haemophilia Treatment Centre (HTC) staff terrified us with their textbook medical talk. In simple terms, they told us we got a bleeder as I made a mental note of the words 'incurable' and 'lifelong', which I would have to get clarification on at a time when I wasn't so hysterical. That day, we learnt that Elias has a rare blood disorder where he is missing the 'factor' that makes his blood clot when he has a cut or bruise.

Coming to terms with Elias' blood disorder as well as managing and preventing any slips, trips and falls became my next mission. I was on high alert 24/7, waiting to see what accidents would happen. Understanding how this disorder would play out meant a tough year lay ahead for our family. There were many trips to our HTC that year, which is conveniently located only 10 minutes away (including the drive through Maccas that was required for sustenance). The first year was definitely the most challenging, as it would be for any parent managing a health condition. However, we have found over time his disorder to be very manageable.

Due to the first-class management and treatment of Elias at our local HTC coupled with the ongoing support and information we received from Haemophilia Foundation Australia (HFA) and HFNSW, the condition has never been more than a slight inconvenience to us. If I could sit Elias down and ask him directly for comment (he's two), he would blabber something about not even noticing he had a disorder, because his life is comparable to any other toddler boy. We often forget about it until someone asks how he's going and we realise he's growing so fast without any hindrance to his social or physical development.

Haemophilia Foundation NSW holds an annual Haemophilia Family Camp for its members, where families connect with other people living with bleeding disorders. It is run by Tony Wilkinson, who does a fantastic job in running this program to help children and those affected gain self-confidence, form new friendships and develop resilience. There are also educational sessions lead by HTC health professionals and youth mentors. We have attended each year since Elias' diagnosis, and it's a wonderful opportunity to catch up with other families and just enjoy some recreation time.

Recently, I found out through genetic testing that I am a carrier of the gene. In general chit-chat, our HTC doctor told me the genetic test results came in and I'm the genetic link. Surprise! Actually, I didn't feel surprised, worried or upset at all. Many women upon finding out they are a carrier can feel guilty, overwhelmed, angry and a mix of negative emotions. Really, there's no right or wrong way to react, as everyone is different. Today, the medical field have an abundance of knowledge about haemophilia, with more research carried out each year.

So now that the lab has spoken and following several weeks of family planning, we have our mission set to Operation Baking of Baby, knowing that if we bake a boy, there is a 50/50 chance of him having haemophilia and a 100% chance of him being delicious. If we have a girl, there is a 50/50 chance that she will be a carrier and may or may not also have mild haemophilia. There is an equally high probability of deliciousness too.

I am currently tipping into my second trimester with baby #2, and in a few weeks, we will find out the gender. The place of birth will be at our local public hospital where the adult HTC is located, and our HTC will work with the obstetric team in developing a birthing plan appropriate for a baby with haemophilia. As we had no knowledge whatsoever of Elias' condition at the time of his birth, forceps were used during delivery. We were lucky there was not a subsequent head bleed, and in general he was a healthy baby! This time round we have all our reinforcements in place (pretty much an army) to help plan and recommend safe birthing methods, as well as supply factor and support. We're in good hands!

For those parents who have received the news of a haemophilia diagnosis for their son, relative or loved one, I encourage you to get as acquainted with the HTC staff, the Haemophilia Foundation and support network as much as possible. Over time, you will come to trust their knowledge and expertise, whilst having the challenging yet rewarding privilege of helping a child to live an abundant life without limits.

Alex Coombs is Social Worker – Haemophilia & Other Inherited Bleeding Disorders
at the Ronald Sawers Haemophilia Treatment Centre, The Alfred hospital, Melbourne

TAKE CONTROL

Alex Coombs

The right documentation can give you some power over your future medical care and treatment.

THE UNEXPECTED

As some of you may recall the 10th March 2011 was a day my life and world changed for me. Until that date I had been living my life fairly carefree, travelling and working as a social worker at the Alfred hospital Infectious Diseases Team and Ronald Sawers Haemophilia Treatment Centre for three years. I had relocated from Perth, where I had lived all my life to start in a new social work clinical area and enjoy the many great lifestyle options Melbourne had to offer.

You never know what is waiting ahead and the changes that can occur in an instant. I still remain unable to explain why I went from planning to head off to work one morning as I stood on my third floor balcony to now being reliant upon an electric wheelchair and personal carers every morning 7 days a week six years later.

Like many people I hadn't given much thought about the "what ifs'. I had a unit I planned to hold onto, and had dutifully done my will that made provisions for my estate and any remaining extended family in Perth. Being single and away on the other side of Australia from my family, who would be responsible to make medical or financial/ lifestyle decisions on my behalf if I wasn't in a position to do so one day? Even if I was partnered too, it is not as clear-cut as you or even best friends know.

ADVANCE CARE PLANNING

I recently attended a workshop on Advance Care Planning, which is a way to ensure your thoughts and wishes about your medical care and treatment can be recorded and known by your GP, treating team and hospital and your family/significant others. I add that the guidance and input of the medical team is still highly sought and not to be ignored in any aspect of this. As we age our body keeps changing, no matter how healthy we think we are or attempt to be. For those with existing medical conditions this can add more complexity and risk.

I am not trying to sound alarmist but to bring to your attention that there are a few ways that we all can ensure that our wishes for medical intervention can be communicated to your medical team, treating hospital or if you find yourself in another hospital not familiar with your medical history.

SUBSTITUTE DECISION MAKERS

Who should know your wishes regarding your health and medical decision making if you can't communicate them yourself? Well let's start with your significant other(s). Whether you are married, de-facto or single it can become essential someone has recollection of what you want regarding treatment or level of intervention to either restore your health or keep you comfortable and pain free. The person who makes these decisions on your behalf when you cannot is known as a "substitute decision-maker". I would recommend people appoint a substitute decision-maker and potentially an Advance Care Plan to capture your wishes to their fullest degree and avoid the potential for conflicts to arise between family and significant others.

The timing of having a conversation with your chosen confidante about your wishes, in my opinion, would be best when you are at your healthiest and competent. You may have recently had an event that began to make you think 'what if'. We can all make assumptions about who takes over, even I did as a social worker after almost 20 years in health.

WHO WILL DOCTORS TURN TO FOR MEDICAL DECISIONS?

When a treatment decision has to be made and you do not have the capacity to make it, the medical team will turn to a specific hierarchy of decision makers based on the level of connection to you as the patient. Whilst all relationships will be respected generally in the health care system, the powers to make decisions about medical treatment for you when you cannot are considered to be very important under the law. In all Australian states and territories except NT, the medical team must use a legislated hierarchy for the substitute decision maker

that follows legally recognised relationships and blood family connections. Depending on which state or territory you live in, this person might be known as the "person responsible" or the "[statutory] health attorney".

Who is this person? The first person the medical team will turn to is someone you have appointed legally. If you have not appointed anyone, then depending on which state or territory you live in, they will be required to turn to your spouse, or if you don't have one, your nearest relative or unpaid caregiver.

WHO WOULD YOU CHOOSE?

Usually when we are admitted to hospital, we, or someone on our behalf might fill in a registration form with the words: "next of kin", "Emergency Contact", "person responsible" requiring name and contact details. Whilst helpful, do this person know what we want to happen to us from the medical treatment point of view? What if our personal, religious, spiritual or cultural beliefs influence our thinking? Would the person whom the treating team talk to know how important that is to us?

If you would choose someone different to the "person responsible" or "health attorney" or "next of kin" or you don't have anyone who fits the criteria, your next option is to appoint someone you trust as your substitute decision-maker. If no one fits that criteria for you, you can ask for a publically appointed person to be applied for. The person you have appointed will have the powers to make decisions on your behalf when you are unable to do so due to an accident or illness. This is one area that can give power to those who are in a same sex attracted relationship, those without close family ties living or close by or due to family dysfunction. Bear in mind that if you are in a same-sex relationship, this is usually not recognised under the law in your state/territory, and you may need to appoint your partner legally as your substitute decision-maker to have them as the first person to turn to in the legal hierarchy of medical decision-makers.

HOW DO YOU DOCUMENT YOUR DECISION-MAKER AND WISHES?

Each state and territory has legal documents you can use to appoint someone as your preferred substitute decision-maker and legal documents to record your wishes.

See ROLES AND DOCUMENTS for more information.

Before you go ahead and document your wishes and sign it off, PLEASE inform the appointed person that you intend to do so and discuss your wishes with them. They don't need another sudden surprise during a traumatic hospital situation to be told they have a significant level of responsibility on your behalf.

ROLES AND DOCUMENTS

- Next Of Kin – the closest living relative such as wife, husband, domestic partner, sibling with whom your medical team will discuss your medical situation with but may not be the person legally deemed to be the substitute decision maker, if that applies in your state or territory - see below.

- Emergency contact – similar to the above but a person who can be nominated to go between you, your medical team and the outside world of family and friends

- Guardian – legally appointed person to make decisions if you have no one else capable or willing to do so

- Person responsible/statutory health attorney/health attorney – is the first person in a legislated list of relationships who is available, willing and able to make decisions about your medical treatment. In all Australian states and territories except NT, the relationships in the list will include the following, although their place in the hierarchy varies from state to state:

>>

Person appointed legally to undertake medical decisions on behalf of the patient

Spouse or domestic partner

Primary unpaid caregiver

Nearest relative aged 18 and over, which may mean the oldest.

In some states, a close friend

- Legally appointed substitute decision-maker - is a person given legal authority by you to make medical decisions when your own capacity is diminished.

  Depending on which state or territory you live in, this person might be known as:

  An enduring guardian

  An enduring power of attorney (Medical treatment/Healthcare matters/ Personal matters)

  An agent

  A decision-maker.

  You will need to complete an official form provided by your state/territory government to appoint someone as your substitute decision-maker. See www.advancecareplanning.org.au for the appropriate forms in your state/territory.

  There are other substitute decision-maker roles where you can appoint someone else to manage your financial and lifestyle affairs, such as an Enduring Power of Attorney (Financial matters). If you have any of these forms completed, please ensure your GP, hospital, medical team, case manager, social worker, family and significant friends are aware of their existence. A copy should be noted as a true and sighted copy to be held in your medical records. If you attend other hospitals ensure they each similarly have a copy.

- Advance care plan - records your wishes in regard to the types and level of medical intervention you wish to be carried out in emergency and life threatening events. If you have recorded your wishes in one of these documents, I would recommend that you can arrange for another copy to be held by in any hospital where you already have a medical record and are likely to be admitted.

  The name of the advance care plan document varies from state to state. Se e www.advancecareplanning.org.au for the appropriate forms in your state/territory.

The documents for your substitute decision-maker and advance care plan are very important to ensure that your appointed decision-maker is consulted and can work together with your medical team to be guided by your documented wishes. You may wish to consider the advantage of these documents being on file in your medical records.

By writing this, as a social worker I hope it will give rise to more careful documentation of our client's wishes and decision-making. These documents enable us to have conversations with our clients to ensure their health beliefs are recognised and followed by those often left to make hard decisions at difficult times.

MORE INFORMATION

Advance Care Planning Australia – www.advancecareplanning.org.au
Includes information about substitute decision makers and advance care planning documents and forms for each Australian state and territory

Australian Dept of Health - LGBTI Advance Care Planning by State and Territory - http://tinyurl.com/lgbti-ACP

MyAgedCare – Advance Care Planning - http://tinyurl.com/myagedcare-ACP

Carter RZ, Detering KM, Silvester W et al. Advance care planning in Australia: what does the law say? Australian Health Review 2016;40:405–414. http://dx.doi.org/10.1071/AH15120.

CHANGE TO MYABDR REMEMBER ME FUNCTION

From the National Blood Authority and HFA MyABDR teams

From Tuesday 22 August 2017 if you want to use the REMEMBER ME function on the MyABDR app, you will need to set a 4-digit pin.

To set the PIN, at the login screen tap the REMEMBER MY DETAILS button NOT LOGIN.

WHY HAS THIS CHANGE OCCURRED?

You may be aware of the current concerns at a national level about the protection of personal information.

Protecting ABDR/MyABDR users' personal information on mobile devices and computers, while preserving favourite functionality has been a subject of considerable discussion between the National Blood Authority and HFA.

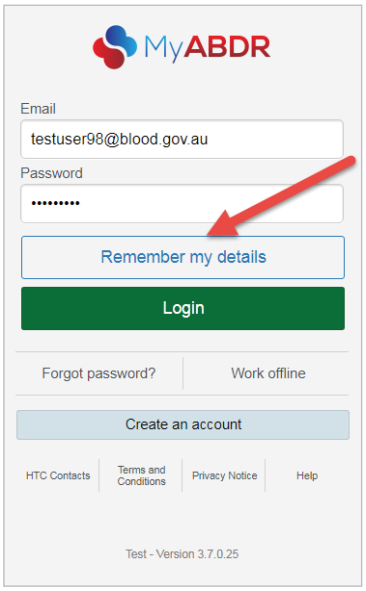
Against this background the NBA has implemented a simple solution of a four digit pin lock to access MyABDR on your mobile device.

This solution is only required when accessing and using MyABDR and does not impact on the use of your mobile device. The pin lock is very similar to other applications such as online banking.

The enhancement to the 'Remember my details' functionality means that you can continue to use this option knowing that your access to the ABDR/MyABDR system is now more secure.

HOW WILL THIS WORK?

- When you tap the REMEMBER MY DETAILS button at the LOGIN screen, you will be invited to set a 4-digit PIN.
- Whenever REMEMBER MY DETAILS is activated, you will need to use your 4-digit PIN to login if you have not used MyABDR in the last 30 seconds.
- However, when you are logged out and need to login again, you will still need to enter your email and password – BUT!!



- If you want to use the 'remember me' functionality, you should tap on the REMEMBER MY DETAILS button rather than LOGIN to login, and then set or reset your PIN.

OTHER SECURITY IMPROVEMENTS

The National Blood Authority rolled out the new PIN functionality with other security improvements in the MyABDR release on 22 August 2017:

- Security improvements to the website version
- New messages on the mobile app where the device is insecure
- MyABDR will no longer be accessible from 'rooted' or 'jailbroken' devices.

ANY QUESTIONS OR NEED HELP?

Contact the MyABDR Support team (24 hrs, 7 days a week)

T: 13 000 BLOOD / 13 000 25663
E: support@blood.gov.au.

MYABDR USER SURVEY

HFA and National Blood Authority MyABDR teams

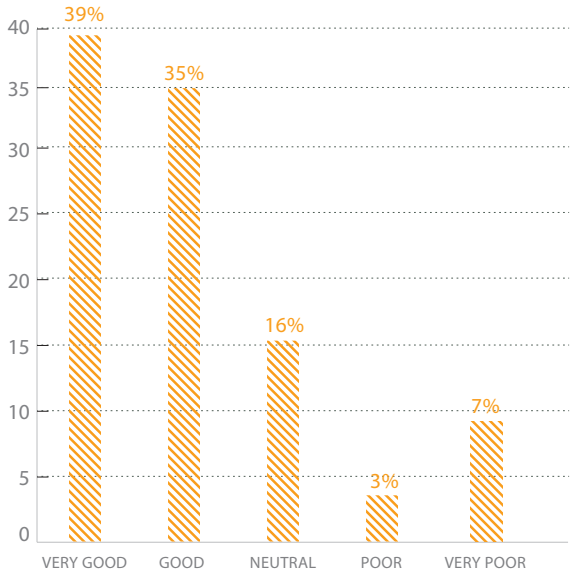
In June 2017 HFA and the National Blood Authority (NBA) put together a survey for MyABDR users to gather feedback on the current app and website and ideas for future enhancements.

MyABDR is the secure app and website for people with bleeding disorders or parents/caregivers to record home treatments and bleeds and manage their stock inventory. It links directly to the Australian Bleeding Disorders Registry (ABDR), which is the system used by Haemophilia Treatment Centres around Australia for the clinical care of their patients. Released in 2014, MyABDR is a collaboration between HFA, the Australian Haemophilia Centre Directors' Organisation (AHCDO) and the NBA on behalf of all Australian governments, and it is reviewed and improved regularly with feedback from the community and Haemophilia Treatment Centres.

This survey was an important opportunity to see how users are finding MyABDR and consider what might improve their user experience. Our thanks to the people who gave their time to respond.

USER EXPERIENCE

Overall experience of using MyABDR



WHO RESPONDED?

94 people completed the survey.

49% had a bleeding disorder

51% were parents/guardians of children with a bleeding disorder

3% were the partner/caregiver of someone with a bleeding disorder

WHAT DEVICE FOR MYABDR?

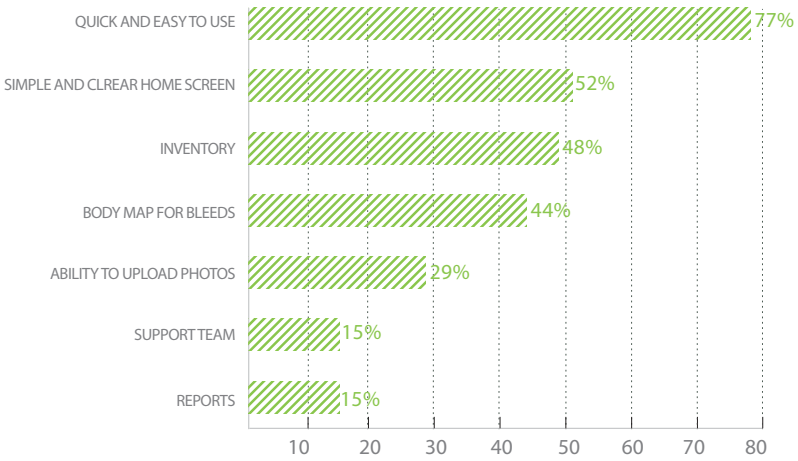
42% used a computer

42% used an iphone

27% used an Android phone

21% used an ipad or Android tablet

Which MyABDR feature do you like?



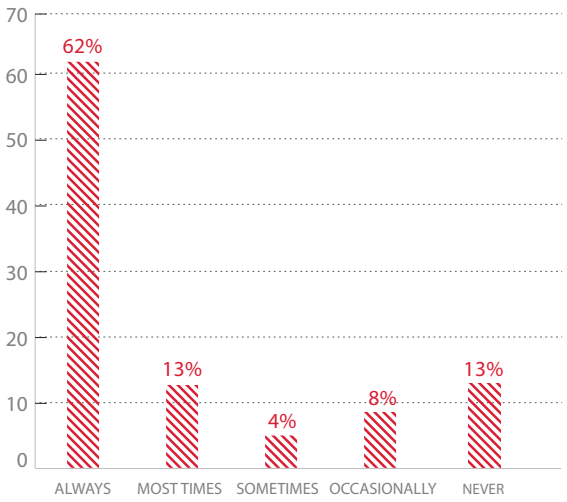
Least useful features

11 users thought all MyABDR features were useful; 3 did not like any of the features.

28 users made comments on specific features. . The main comments were:

- Treatment plan – not current; also needs doctor contact information for Emergency Department visit
- Body map – not specific enough for actual bleed location
- Inventory stock quantity – difficult to match what is actually at home, or if you have treatment at another hospital and want to record
- Expiration date – doesn't relate to product on hand.

RECORDING TREATMENTS AND BLEEDS
How often do you record treatments and bleeds on MyABDR?



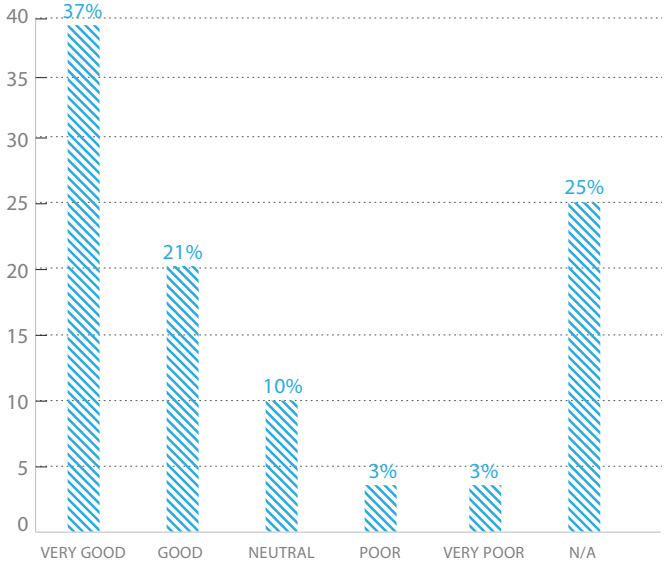
What gets in the way of recording?

- Time – are busy; forget to record afterwards
- Can't remember how to use MyABDR when not used for a while
- Poor reception
- Entering batch numbers, especially with poor eyesight or arthritic fingers
- Many steps that take time if you are not dextrous
- Can't edit hospital entries or inventory if these are wrong
- Problems with inventory then can't record treatment
- Not enough bleed options for females
- Can't record bleeds in multiple body locations easily
- Needing to re-enter or reset password
- Treatment is with product that is not in the list
- On a clinical trial and can't use MyABDR.

Suggested improvements

- Barcode scanning of batch numbers
- Reports on mobile app like on the web version
- Summary list of bleed treatments
- Home delivery stock details automatically added to the MyABDR inventory
- Reminders for prophylaxis treatment
- Fewer steps and screens for login and recording.

SUPPORT AND EDUCATION MATERIALS
Rate your experience with the MyABDR support team



"They are always available and on the ball. Great support team!"

Many of the survey respondents commented that they were not aware of the support team or of the support materials available on the MyABDR website - https://www.blood.gov.au/myabdr. This is clearly an area for more active promotion to users.

WHAT HAPPENS NEXT?

The HFA and NBA MyABDR teams will review the results together and look at what can be dealt with immediately. This may include advertising the support team and the support materials more widely and agreeing on next steps for identified enhancements.

There are some improvements already in the pipeline:

- Barcode scanning of batch numbers – planned for 2018 once updates are completed to the barcodes by suppliers
- Updates to how treatments and bleeds are recorded, in particular the use of the body map and ability to record multiple bleed locations and multiple products.

Look out for the MyABDR update articles in your Foundation newsletters for more information about this.

And a reminder that you can provide feedback on MyABDR at any time:

- with the MyABDR feedback form - http://tinyurl.com/myabdr-feedback
- or to the MyABDR Support team

T: 13 000 BLOOD (13 000 25663) **E:** myabdr@blood.gov.au

WORLD HEPATITIS DAY

World Hepatitis Day is marked internationally on 28 July.

This year we celebrated World Hepatitis Day with the stories of people with haemophilia and von Willebrand disorder who have been cured of their hep C.

A NOHEP FUTURE

In 2017 the global community has come together in support of the World Health Organisation's commitment to eliminate viral hepatitis by 2030.

Imagine a future without hepatitis C.

Can we achieve this in the Australian bleeding disorders community?

I AM CURED OF HEP C

The new direct acting antiviral (DAA) hepatitis C treatments are truly revolutionary. In Australia they are available on the PBS (Pharmaceutical Benefits Schedule), which means they only cost as much as any prescription medication. Hepatitis and haemophilia specialists are encouraging everyone with hepatitis C to come forward for treatment.

- High cure rates - 95% overall
- Few if any side effects
- Tablets – no injections
- Shorter treatment courses – 8-24 weeks.

We are pleased to hear from Haemophilia Treatment Centres that most people with bleeding disorders have now been treated and cured of their hep C.

"I was handed the printout of results. The three words I knew would be there, were there: VIRUS NOT DETECTED. I was cured!!!!" Len

"Having had the new treatment and being cured has had a big impact on my quality of life. I have noticed over the last few months that I have a lot more energy. I used to go to work and then go home and feel really tired, now I get home and tinker about in the shed or whatever for a couple of hours if I feel like it." Paul

"I feel a lot better knowing I don't have hepatitis C anymore. I'm going to be around a bit longer!" David

I AM CURED VIDEO

What is it like to have the new treatment and be cured?

Paul and Len tell their stories in our new video - **Hep C - I am cured!** – https://tinyurl.com/hepc-cure

You can read their full stories at http://tinyurl.com/hepc-stories

WHAT CAN YOU DO TO HELP?

- Spread the word!
- Many people with bleeding disorders were exposed to hep C. Have you ever been tested? If you used factor before 1993 – even as a baby – you could be at risk. Act now – if you don't know whether you have hep C or not, get tested!

  "If you don't know if you have hep C, get tested. It was just a fluke thing that I found out. But if I had known earlier that I had hep C, I probably wouldn't have cirrhosis of the liver because I could have had it treated back years ago." David

- If you have hep C, talk to your doctor about treatment that could cure your hep C

Don't wait for warning signs

If you have hep C, talk to your doctor about treatment. It's easy and it could save your life.

WHAT'S STOPPING YOU FROM TREATMENT?

HFA is keen to make sure that every Australian with a bleeding disorder and hep C has the opportunity to have treatment as soon as possible. However, we are aware that some people experience barriers that stop them from accessing treatment.

- **Don't wait until you have symptoms of liver disease to start treatment.** Liver disease with hepatitis C can advance silently and you may not be aware that you are developing advanced liver disease such as cirrhosis or liver cancer.

  Treatment is easy
  "How difficult to take? Pop them [tablets] in your mouth at the same time each day and wash down with a glass of water." Len

  "The new treatment was nothing like the interferon treatments. I had one tablet a day every morning for 24 weeks." Paul

- Worried about side-effects?
  "For the first two weeks I had some side-effects while my body got used to it: fatigue, a little bit of nausea. But after that there was nothing much; life just returned to normal. It didn't affect my work." Paul

  "The side effects? Nil." Len

- Hard to get to the hepatitis clinic?
  Talk to your hepatitis clinic or HTC about working with your local doctor. If you don't have cirrhosis, hepatitis C treatment can now be prescribed by any doctor or nurse practitioner experienced in hepatitis C treatment, or any doctor can prescribe in liaison with a hepatitis specialist.

- If you have cirrhosis
  You would need to see a hepatitis specialist for your treatment, but they can often arrange to have some of your testing done locally to minimise trips to the specialist. Having cirrhosis might mean a longer course of treatment, but cure rates are still very high.

- Is something else stopping you from getting hep C treatment?
  Talk to your HTC or Foundation about solutions. Change your future today!

MORE INFORMATION

- HFA Hep C treatments page - https://tinyurl.com/new-hepc-treatment
- World Hepatitis Day page - http://www.worldhepatitisday.org.au

HFA is a Partner in the national World Hepatitis Day Campaign and works with Hepatitis Australia and State and Territory Foundations on key messages. Thanks to Hepatitis Australia for permission to adapt the 2014 World Hepatitis Day poster and to the HFA World Hepatitis Day Working Group for developing the campaign for the bleeding disorders community.

Eliminating viral hepatitis

NOhep

HEP C NEWS

From 1 August 2017 a new hepatitis C treatment has been made available on the PBS to treat people who have any strain of hepatitis C virus (HCV). Epclusa® is a once-daily single pill treatment for 12 weeks, with cure rates of more than 90% no matter which HCV genotype the person has.

"We welcome the announcement from Federal Health Minister Hunt that this new treatment will be subsidised so that it can be accessed by all Australians," said HFA President Gavin Finkelstein.

"This last year has been a very exciting time for the bleeding disorders community. So many people are finally cured of their hep C with these new treatments – and with very few side-effects, if any. But there are still some people who haven't had treatment yet.

"Treatments like this that are easy to prescribe and easy to take make it simpler for both the doctor and the person with hep C. This means that some people who live some distance away from the specialist centres can see their local doctor for their treatment.

"The Australian Government is committed to eliminating hep C in Australia by 2030 and we would like to achieve this much earlier in the bleeding disorders community. I urge all community members to take this opportunity to be cured. If you or someone you know with a bleeding disorder and hep C has something that is getting in the way of treatment, we invite you to speak to us so that we can find a solution together."

As of 1 August 2017, there is now a range of new interferon-free Direct Acting Antiviral (DAA) treatments for all genotypes of hepatitis C:

- **Epclusa®** - sofosbuvir with velpatasvir
- **Harvoni®** - sofosbuvir with ledipasvir
- **Sovaldi®** - sofosbuvir
- **Daklinza®** - daclatasvir
- **Viekira Pak®** - ombitasvir, paritaprevir, ritonavir, dasabuvir - tablets with or without ribavirin
- **Zepatier®** - grazoprevir + elbasvir

HFA has been working with the Australian Haemophilia Centre Directors' Organisation (AHCDO) and hepatitis specialists on a fact sheet for general practitioners on people with bleeding disorders and hepatitis C to answer any questions GPs may have around testing and treatment. This is intended to be used alongside the updated Australian recommendations for the management of hepatitis C virus infection: a consensus statement[1], which will be released shortly. The GP fact sheet will be available on the AHCDO and HFA websites.

REFERENCES

1. Hepatitis C Virus Infection Consensus Statement Working Group. Australian recommendations for the management of hepatitis C virus infection: a consensus statement. Melbourne: Gastroenterological Society of Australia, 2017.
Latest edition available on the website < http://www.hepcguidelines.org.au>

Suzanne O'Callaghan is HFA Policy Research and Education Manager

POLICY UPDATE

Suzanne O'Callaghan

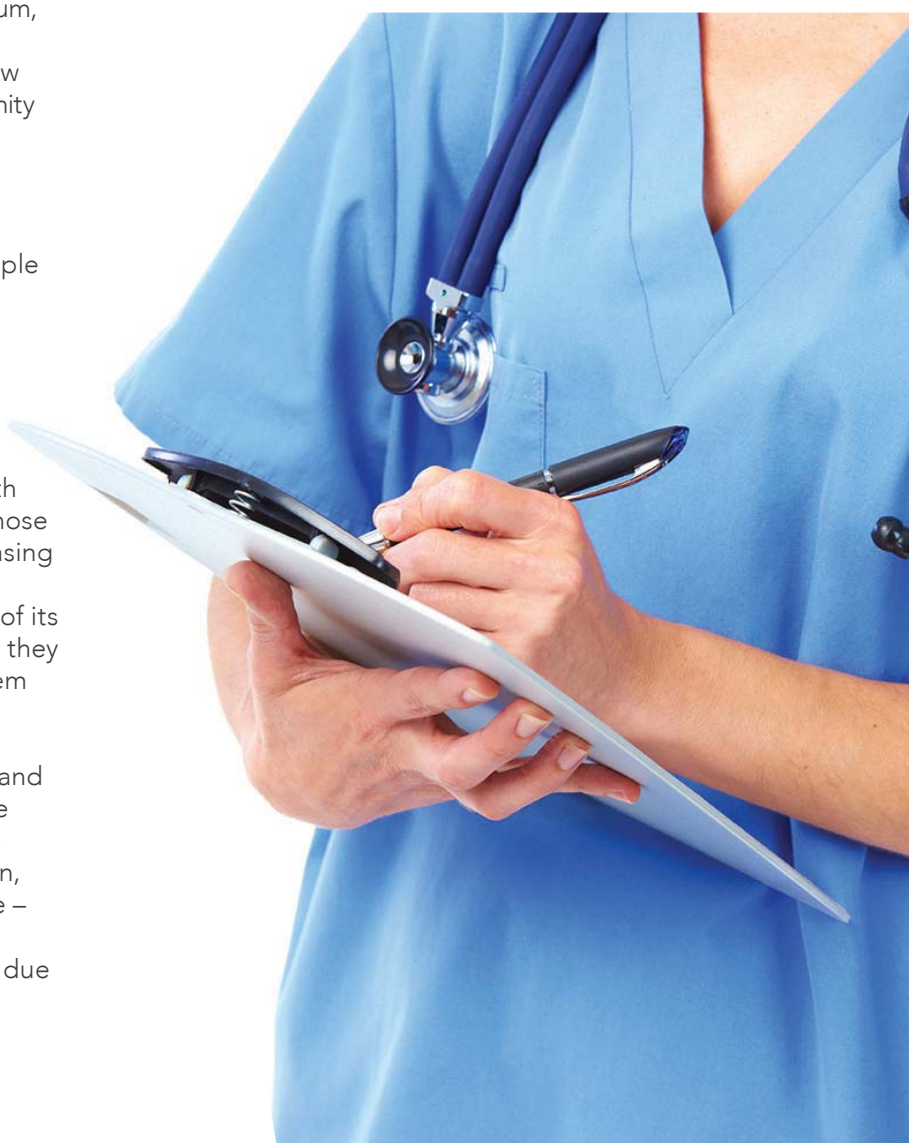
PRIVATE HEALTH INSURANCE INQUIRY

How does the current situation with private health insurance in Australia impact on the bleeding disorders community? This might seem a strange question, seeing that people with bleeding disorders receive most of their care for their bleeding disorder through the public health system, but in fact this highlights some of the complexities for our community.

HFA regularly makes submissions to government when there are issues that affect people with bleeding disorders. In a broad area, such as the current Australian government inquiry into private health insurance, HFA will liaise closely and share information with the Consumers Health Forum, both as a member organisation and because of their expertise. At the same time, it is very important to know what specific concerns there are directly from community members and HFA ran a community survey on private health insurance in July 2017.

In a short timeframe of 10 days HFA had received 70 survey responses – an indication of how strongly people felt about this issue. Many used the private health system for some aspect of their health care – as a private patient in a public hospital, or to manage health issues not related to their bleeding disorder, or for extras such as optometry, hearing aids, dentistry, physiotherapy, etc. They were very concerned that the premiums for private health insurance were becoming unaffordable, even for those on middle incomes, while the benefits were decreasing sharply. Others commented that they had private health insurance for tax purposes but were unsure of its value to them otherwise as benefits were poor and they were largely required to use the public health system because of their bleeding disorder.

These survey comments were immensely valuable and formed the backbone of the HFA submission to the Inquiry. Our thanks to all those who completed the survey. If you would like to read the HFA submission, you can find it on the Inquiry Submission web page – submission number 50 on http://tinyurl.com/privatehealth-sub. The Inquiry is due to report in late November 2017.



isth 2017 CONGRESS

Sumit with the bear symbol of Berlin

At the International Society on Thrombosis and Haemostasis (ISTH) Congress the world's leading experts on thrombosis, haemostasis and vascular biology come together to present updates on recent research and discuss the newest clinical advances to improve patient care. The 2017 Congress was held in Berlin, Germany and over 9000 delegates attended.

With a theme of **Transcending Scientific Boundaries** and an extensive line up of educational sessions, poster and oral communications, the program fostered sharing of knowledge and promoted important scientific discourse and advancement.

The ISTH reports from Andrew Atkins and Sumit Parikh give a flavour of the depth and range of the presentations and the challenging debate about new treatments, including gene therapy.

Andrew Atkins is Nurse Consultant, South Australia Adult Haemophilia Treatment Centre

EXPLORING NEW THERAPIES

Andrew Atkins

At ISTH 2017 there was a large interest in the latest developments in haemophilia care. The program was well structured with the opportunity to hear presentations on similar topics over different days.

PERSONALISED TREATMENT REGIMES

Speakers in one of the opening sessions discussed the trough levels (ie, the lowest concentration level of the drug before the next dose is administered) now considered achievable for patients on extended half-life (EHL) products for factor VIII (8) and factor IX (9) and the associated cost. EHL products are now in use in some countries, and so the ability is now there to treat people with haemophilia according to their individual half-lives, bleeding patterns and lifestyle, rather than simply reaching a 1% trough level before administering a next dose. In Australia there are now at least two new mathematically-based programs to calculate one's factor VIII or IX half-life. These programs require less blood tests, making them more convenient, and also provide the ability for a more personalised and more achievable treatment regime.

A debate followed over the use of extended half-life factor IX versus gene therapy. Which is better? Laser eye surgery was used as an example. It was pointed out that while laser treatment is available to correct vision, most people choose to opt for wearing glasses because they are an adequate 'fix' with known side effects…this was countered that gene therapy is seeing promising results and without investigation we will never move forward to better treatment.

EMERGING THERAPIES

A number of talks centred on the new therapies, and outlined what they were and their mode of actions. Other than extended half-life factors, emerging concepts/agents for haemophilia include:

Products that mimic clotting factors – emicizumab (ACE910) is an antibody manipulated to bridge activated factor IX (9a) and factor X (10) and therefore replace the action of factor VIII. It has a half-life of 4-5 weeks and is being trialled as a subcutaneous injection, either weekly, fortnightly or monthly, for the treatment of haemophilia A with and without inhibitors. The Haven-1 study results for people with haemophilia A with inhibitors (109 participants) were outlined showing a reduction in annual bleed rates of 87%. There were zero bleeds in over 60% of patients who were randomised to a prophylaxis regime. Serious thrombotic events were seen in 5 patients with inhibitors when bleeding events were treated with their previous by-passing agent treatment regime. This has resulted in strict treatment guidelines for the use of bypassing agents in conjunction with emicizumab.

Australian nurses at ISTH. L-R: Robyn Shoemark, Andrew Atkins, Megan Walsh, Helen Starosta, Alex Connolly

The Haven-2 (paediatric study) initial findings were also presented showing promising results. Haven-3 and 4 studies are currently underway to study emicizumab in people with haemophilia A without inhibitors and the results of these trials are eagerly awaited in the haemophilia community worldwide. Three other studies involving different drugs/mechanisms are also being developed for trials.

Products that suppress the body's natural clot regulators to offset the effect of haemophilia – studies looking at the effects of reducing either anti-thrombin or anti-TFPI (tissue factor pathway inhibitor) are being planned. These products intend to protect against bleeding using a completely different method than simply replacing the missing factor. Reducing the naturally occurring thrombin inhibitor will increase thrombin generation and therefore offset the propensity to bleeding in haemophilia. TFPI's natural effect is to self-limit one of the pathways of clotting, so reducing its levels is also aimed to protect against bleeding. Trials with these products as subcutaneous injections are aimed with haemophilia A or B.

Gene therapy to restore factor production via a single intravenous injection - after following results for over 6 years in one haemophilia B study, mean factor IX levels rose to 5%, and in a more recent study to over 15% after one year. Both studies have seen a 90% reduction in annual bleed rates and factor IX use. For haemophilia A, initial results in one study outlined saw factor VIII peak levels ranging from 12% to 271%, with levels remaining increased after 44 weeks. An immune response side effect was seen in 25% of study participants, but in all cases were treatable with steroid.

NURSE FORUM

Alongside the opening days of the Congress were two Nurse Forum days. This is the first time two days have been allocated. It provided a great opportunity to hear practical advice about nursing practice in Germany, approaches to research, and nurse-led research. While much of the presentations concentrated on clotting disorders there were a number of thought-provoking talks on managing bleeding disorders. One particularly enjoyable theme centred on challenges facing both patients and nurses in religiously diverse communities (Amish, Muslim and Jewish) – ways of managing these select groups gave insight into thinking outside the square when providing care in extraordinary circumstances.

Five nurses from around Australia were fortunate to be able to attend the Congress. It was well worth attending and hopefully more nurses will be able to attend the 2019 Congress in Melbourne.

>>

Sumit Parikh is the AHCDO ABDR Senior Research Fellow

STANDARDS AND DEFINITIONS

Sumit Parikh

It was highlighted that evaluating safety/efficacy of novel drugs after product registration in a harmonised and standardised way could help to understand how to optimise the data collection.

ISTH 2017 was all about showcasing and discussing the most recent advances in prevention, diagnosis and treatment of thrombotic and bleeding disorders.

AHCDO had two research posters at ISTH this year: 'To characterise current inhibitor status of patients with haemophilia A in Australia' and *'The impact of switching recombinant factor VIII product concentrates on inhibitor development among haemophilia A patients in Australia'.* Both the posters received very good feedback.

Among the many engaging sessions presented that were relevant to the bleeding disorder community there was considerable interest in the Scientific and Standardisation Committee (SSC) sessions.

Standardisation of post-registration surveillance

Post-registration surveillance of a treatment product occurs after a medicine has been approved by a regulatory authority. The current method to evaluate post-registration surveillance does not include registration of all side effects related to existing and upcoming treatment products. It was highlighted that evaluating safety/efficacy of novel drugs after product registration in a harmonised and standardised way could help to understand how to optimise the data collection. This will improve the safety surveillance system knowledgebase and thus the provision of comprehensive care services to the patient and could be achieved by:

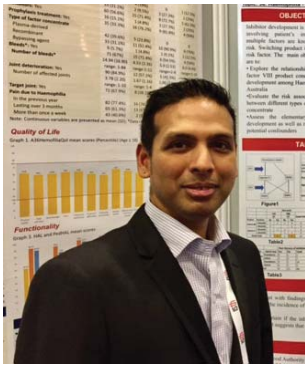
- setting a minimum set of data necessary to bring enough information on safety and efficacy of each single product
- and by approval of this template by regulatory agencies and institutions
- and performing an observational study for at least 5 years.

With so many novel treatment and therapies round the corner, this brings the focus back to the importance of recording data and interactions between patients and their HTC.

Consensus definitions and recommendations for ITI in haemophilia with inhibitors

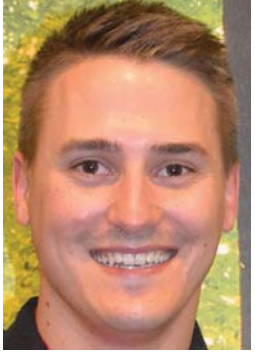
Management of haemophilia with inhibitor patients is complex. ITI (immune tolerance induction) has been highly regarded as an effective method of eradicating inhibitors. This means it is particularly important to establish definitions of ITI outcome and response and to standardise the methodologies to assess treatment endpoints. The characteristics of patient receiving ITI form an integral part of the ITI outcome definition and are essential to be able to provide treatment recommendations and guidelines. This includes information about the patient and their treatment such as:

- age at inhibitor development, and at ITI start
- inhibitor titre, historical inhibitor peak, and peak on ITI
- type of product and treatment dose.



Sumit and Australian haemophilia nurses Alex Connolly, Megan Walsh and Andrew Atkins at the AHCDO posters

Sharon Caris is HFA Executive Director



Griff Farley

Paul Bonner

SA REPRESENTATION

Sharon Caris

The Haemophilia Foundation Australia (HFA) Council is keen to stay connected with the South Australian bleeding disorders community, and continues to look for opportunities to rebuild connections in the community. We hope there will be interest and commitment to re-establishing an organisation to provide peer support, information and education at a local level for families affected by bleeding disorders in time.

TREATMENT AND CARE

HFA maintains strong contacts with specialist health professionals at the Haemophilia Treatment Centres at the Royal Adelaide Hospital and the Womens' & Children's Hospital in Adelaide and is pleased that high quality treatment and care is available to the community around the state. The move to the new Royal Adelaide Hospital commenced at the end of August, and everyone looks forward to seeing the new facilities first hand.

We appreciate the strong input of doctors, nurses and physiotherapists from each of the Centres in work to improve treatment and care for all Australians affected by bleeding disorders through special interest health professional group leadership and membership and through their generous contribution to HFA activities. Behind the scenes haemophilia health professionals from around the country, including from South Australia, contribute to the development of HFA's education resources and programs and policy development. We are grateful for their commitment and time to this work because it benefits the whole bleeding disorders community.

The South Australian community is represented at regular Haemophilia Treatment Network meetings where haemophilia health professionals, data managers and health department officials meet to address new issues relating to treatment and care. Paul Bonner has been a long time community advocate in South Australia, and last year Griffin Farley stepped up to help represent the community at the Haemophilia Treatment Network meetings after Sharyn Wishart moved to the country. Sharyn had been a strong community representative and had also represented HFSA on the HFA Council alongside Rob Christie, then Paul Bonner for several years before HFSA wound up.

COMMUNITY EVENTS

In the meantime, HFA is keen to keep the South Australian community connected with the national bleeding disorders network. We will continue to run a local event or community meetings in South Australia at least once each year, but we do hope there may be opportunity to increase this.

CONFERENCE

All South Australians are welcome to attend the 18th Australia and & New Zealand Conference on Haemophilia & Rare Bleeding disorders 12 -14 October 2017. We have already provided funding to some South Australians to attend, but if you would like to attend and need some financial assistance please contact HFA on hfaust@haemophilia.org.au or phone 1800 807 173 for further information – there is still some funding available, but you will need to be quick!

HFA AGM AND COUNCIL

Paul Bonner and Griffin Farley will be in attendance at HFA's upcoming Annual General Meeting and Council Meeting in October which runs immediately after the Conference, to represent the South Australian perspective. If you have any issues or concerns that you think should be considered by the HFA Council please email Paul on paulbonner1@bigpond.com or Griffin at griff.farley@gmail.com so they can raise them at the Council meeting. We will make sure you are advised of the outcomes of the Council meeting and any specific discussions about the issues you have raised.

Hannah Opeskin is Health Promotion Officer, Haemophilia Foundation Australia

YOUTH **UPDATE**

Hannah Opeskin

Youth Lead Connect (YLC) is a leadership program developed by Haemophilia Foundation Australia (HFA) to build education and life skills for young people with bleeding disorders. The program began in 2015 and follows an application pathway similar to a job application process. The program encourages youth to step up in their local community and increase both their personal and leadership growth.

The 2017 Youth Lead Connect participants are working with HFA and their Haemophilia Foundations towards their personal YLC goals. These goals match skills the youth participants would like to build and strengthen and align with the priorities of their Haemophilia Foundation. Since the training weekend in February, youth have been working on how they can help their Haemophilia Foundation make connections with other youth, encourage young people to attend Foundation events and on developing their leadership and mentoring skills in the community.

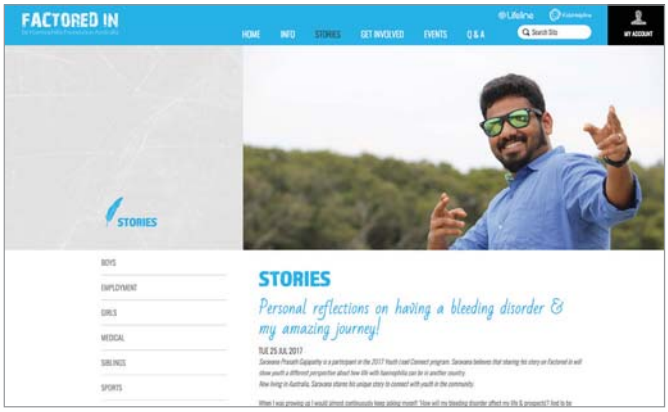
YLC participants' achievements and goals developed as part of the program encourage and motivate them. Their work is visible in their community and engages other young people with bleeding disorders. Their involvement in Youth Lead Connect helps participants to step up in their community as leaders and mentors, and provides a way for them to connect with other youth, community members and community leaders.

Leadership Achievements

- Personal story written and published on Factored In
- A participant has written an expression of interest to gauge interest for a youth event in their state
- Three youth participants have met to discuss and plan a youth event in their state

Leadership Achievements in progress

- The planning of a youth event in a state community
- Development of a youth outreach activity
- A youth participant is working on a personal story about their experience working with haemophilia



HAEMOPHILIA & RARE BLEEDING DISORDERS CONFERENCE 2017

Don't forget that this year, the Australian & New Zealand Conference on Haemophilia & Rare Bleeding Disorders will be on 12-14 October and held in Melbourne. It's almost October, so make sure you register as soon as possible to secure your spot at the conference!

Youth activities at conference: Youth VIP Meet & Greet ~ 7.30pm Thursday 12 October

If you want to meet other members of the youth community or catch up with those you haven't seen since the last conference, then this function is for you! This VIP event is only available to youth who have registered, so make sure you register now!

Youth session – busting myths ~ 10.45am-12.15pm Friday 13 October

This youth session is all about busting myths about living with a bleeding disorder.

The session will cover sport, employment, discrimination, sex, tattoos and more!

If you're interested in attending the conference, visit the HFA website: www.haemophilia.org.au for more information and register now!

YOUTH NEWS

WFH YOUTH LEADERSHIP WORKSHOP

My name is Sam, and I recently had the privilege of being asked by HFA to attend a youth leadership workshop being held by the World Federation of Hemophilia (WFH) to provide an Australian perspective on youth leadership to a group of youth leaders from various haemophilia organisations located around the world.

The workshop was to be held in Panama City, Panama, a short hop, skip and 22hrs of flying away!

After making my arrangements with HFA & WFH to attend, arranging flights and letters from my HTC to take my factor out of Australia, I was finally away!

I had also sort of signed myself up to take part as a presenter on a panel for a Facebook live event that was being held. The panel was about different countries' haemophilia organisations, and their treatment situations, along with information about the youth programs which each country has in place. Thanks to the help of the HFA staff, Sharon, Suzanne & Hannah, I managed to put together a brief presentation.

If you would like to see more of the presentation, you can find the entire event on the WFH Facebook page (http://tinyurl.com/wfh-video-youth), and if you have some spare time, I would recommend having a look, as it gives a bit of perspective as to how lucky we are to have access to free treatment in Australia, but at the same time we obviously can't sit on our hands with the changes that are coming.

The workshop also involved several sessions over 2 days ranging from youth engagement, and how to build engagement, social media training and techniques, planning and managing events, advocacy techniques, and also some sessions on communication, relationships, and challenges of being a young adult with a bleeding disorder.

The workshop was filled with some lovely young leaders from around the world, from places like Nicaragua, Morocco, Saudi Arabi, Korea, Panama, Venezuela, Honduras, Brazil, Georgia, Ukraine, Costa Rica, Bulgaria, Dominican Republic. With presenters from the United States, Canada, Brazil and New Zealand.

It was a full-on and informative experience. And obviously seeing that for most attendees English was not their first language, it was great to see everyone communicating so well together. Regardless of where we all come from, we still share many of the same day to day issues of life with a bleeding disorder.

As a final note to everyone who has taken the time to read this short article, I would encourage you to continue to be involved and connected to the bleeding disorder community and do be afraid to take part in the different events which are held.

Find out more on the WFH website: https://www.wfh.org/

Youth leaders at the WFH workshop, Panama City
Photo: WFH

CALENDAR

Bleeding Disorders Awareness Week
8-14 October 2017
Tel: 03 9885 7800
Fax: 03 9885 1800
Email: hfaust@haemophilia.org.au
www.haemophilia.org.au

18th Australian & New Zealand Conference on Haemophilia & Rare Bleeding Disorders
Pullman Albert Park, Melbourne
12-14 October 2017
Tel: 03 9885 7800
Fax: 03 9885 1800
Email: hfaust@haemophilia.org.au
www.haemophilia.org.au

World Haemophilia Day
17 April 2018
www.wfh.org/whd

XXX111 WFH World Congress, Glasgow, Scotland
20-24 May, 2018
https://www.wfh.org/congress

Haemophilia Foundation Australia (HFA) values the individuals, philanthropic trusts and corporations which have made donations to support HFA activities and programs and sponsorship for programs to enable HFA to:

- represent and understand the needs of the community
- provide education and peer support activities to increase independence and the quality of lives of people with bleeding disorders, and their families
- encourage clinical excellence in haemophilia care, and promote research.

Why the change to Bleeding Disorders Awareness Week?

You may be wondering why this year we are celebrating Bleeding Disorders Awareness Week rather than Haemophilia Awareness Week. This is because we want everyone living with a bleeding disorder to feel supported by Haemophilia Foundation Australia and their local Foundations and to be confident their voice is heard.

Haemophilia Foundation Australia acknowledges the funding and assistance received from the Australian Government Department of Health which makes this publication possible.